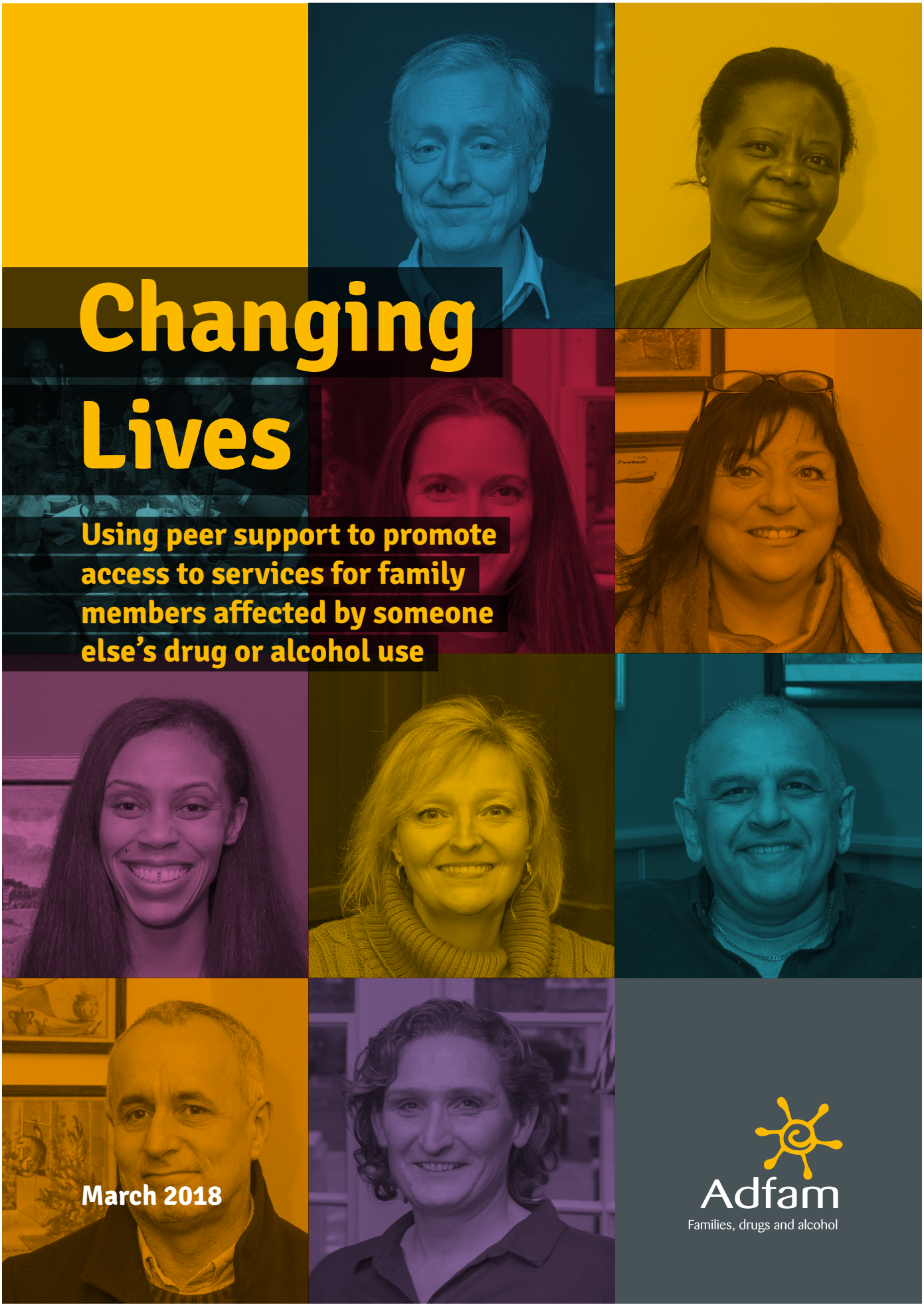

Changing Lives

Using peer support to promote access to services for family members affected by someone else's drug or alcohol use

March 2018

Adfam
Families, drugs and alcohol

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Whole Family Recovery
Introduction

Adfam's Whole Family Recovery Project was funded by the Big Lottery to work with families affected by drugs and alcohol in the Royal Borough of Greenwich.

The grant was awarded to enable Adfam to 'support family members and carers in Greenwich to enable them to become Family Recovery Champions and to develop their own mutual aid groups to assist other families to reach their goal of recovery.' The Family Champions' overall aim was to inspire others to make positive changes in their lives and redress the negative impact of drug and alcohol use in their families and communities.

The purpose of this report is to describe Adfam's Family Peer Support model and highlight the challenges we experienced in order to share our learning.

We hope other family support services and drug and alcohol treatment providers will be able to use and adapt this model, to better address the needs of family members affected by a loved one's substance misuse.

About us

Adfam is the national charity working to improve life for families affected by drugs and alcohol. We want anyone affected by someone else's drug or alcohol use to have the chance to benefit from healthy relationships, be part of a loving and supportive family, and enjoy mental and physical wellbeing. Drug and alcohol use can threaten and ultimately destroy family relationships and wellbeing. We empower family members and carers, support frontline workers and influence decision-makers to stop this happening.

The need:
the evidence

In 2009, the UK Drug Policy Commission estimated that there are at least 1.5 million people in the UK affected by someone else's drug use.[1] However, this figure only includes those family members and carers living with someone using drugs, and only when the drug use is at the extreme end of the spectrum.

Other estimates, based on the assumption that every substance misuser will negatively affect at least two close family members, suggest that the true number is nearer 8 million.[2] Family members affected by a relative's alcohol use are likely to be far more numerous, given the greater prevalence of alcohol misuse in the general population.

Adfam's vision is that anyone affected by someone else's drug or alcohol use has the chance to benefit from healthy relationships, be part of a loving and supportive family and enjoy mental and physical wellbeing. Central to all our projects is a commitment to training and supporting family members to advocate for themselves and each other and to have their voices heard, using peer support and family champion models of service delivery.

Recovery champions

The idea of using 'recovery champions' as part of peer support model is common in the treatment sector, but Adfam was unaware of any projects employing this approach with family members. The model fitted with Adfam's ethos of listening to those with lived experience and working with them to empower them to develop the services and support they require.

Recovery Champions are currently trained and used by many treatment and addiction organisations in the UK and abroad. The 2010 Drug Strategy recognised that Community Recovery Champions – people who are already in recovery, are encouraged to mentor and support their peers, and who contribute to prevention in communities – can effectively motivate others to progress on their recovery journey.[3] These ambitions were recognised and reinforced in the 2017 Drug Strategy.[4]

Recovery is accepted to be more effective where family members are closely involved, yet families need to recover too. They need and deserve to receive help in their own right in order to maintain their own physical and emotional health.

We know that living with a substance user can have a detrimental effect on a family member's health. Research has found, for example, that family members:

- are more likely to be diagnosed with their own medical conditions than non-drug using families, to levels of seriousness comparable with psychiatric outpatients
- suffer stress-related physical and psychological symptoms that can be severe and long-lasting, which are associated with high use of primary care services
- are at a similar or higher risk of disease, emotional issues and behavioural problems to families with a relative suffering from a chronic health condition.[5]

At the outset of this innovative, pilot project, we were not aware of any other service providing training and support for family members as Family Recovery Champions.

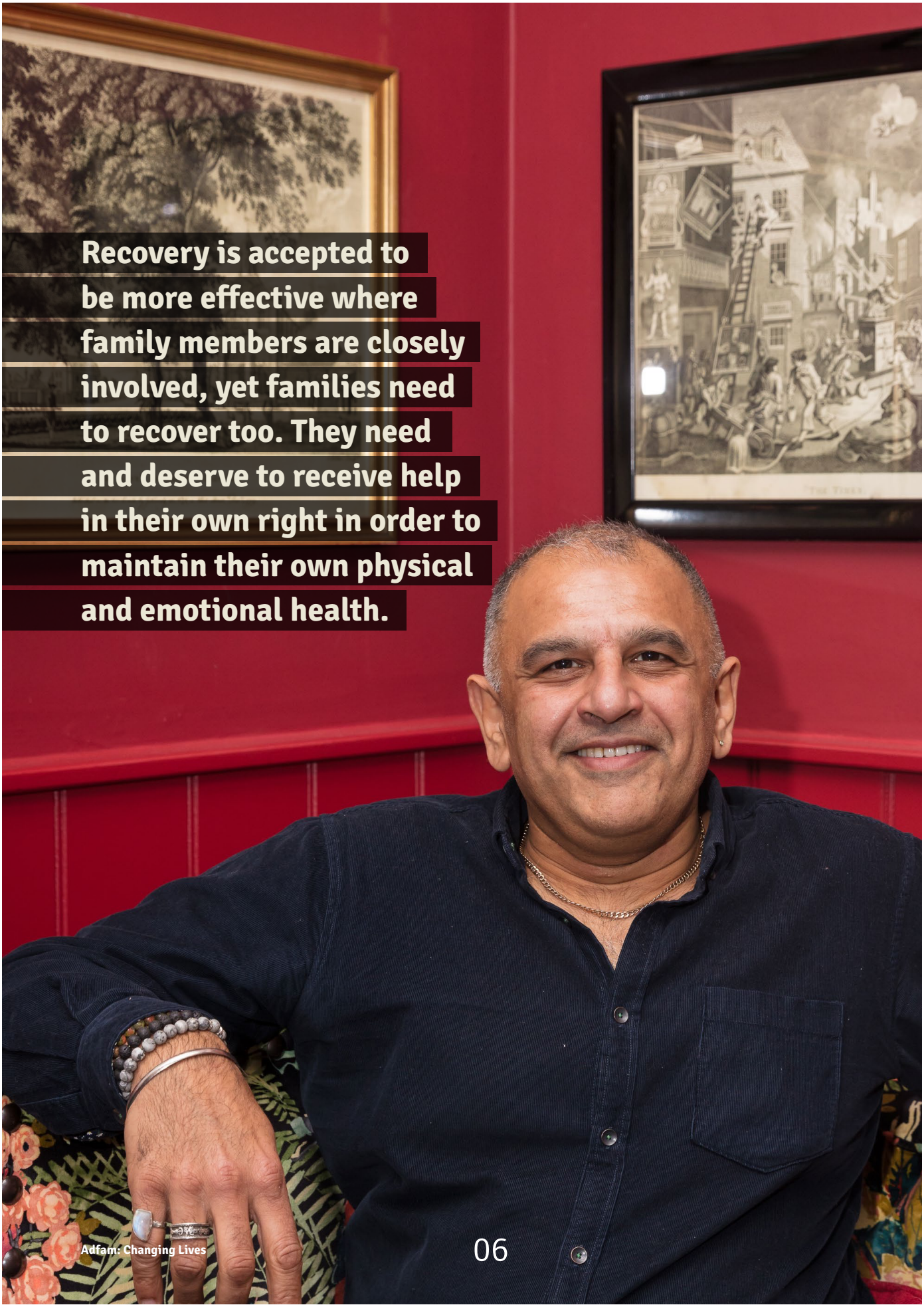
1. Copello, A, Templeton, L and Powell, J (2009). *Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses.* UK Drug Policy Commission.

2. Velleman, R & Templeton, L, (2007). *Understanding & modifying the impact of parents' substance misuse on children.* Advances in Psychiatric Treatment 13 (2) 79–89; DOI: 10.1192/apt.bp.106.002386

3. HM Government (2010). *Drug Strategy 2010 Reducing Demand, Restricting Supply, Building Recovery*.

4. HM Government (2017). *2017 Drug Strategy.*

5. Mertens, J, Thomas Ray, G, Weisner, C (2009). *Family members of people with alcohol or drug dependence: health problems and medical cost compared to family members of people with diabetes and asthma.*


Recovery is accepted to be more effective where family members are closely involved, yet families need to recover too. They need and deserve to receive help in their own right in order to maintain their own physical and emotional health.

What we did:
project design

We designed a project model which built on our experience at Adfam, which indicates that family support should include:

- One-to-one practitioner support: listening, signposting and advice
- Information: on drugs and alcohol, self-care, communication, boundaries, keeping safe, enabling and other important topics
- Peer support: often, but not exclusively, delivered in a group setting.

Adfam believes that the key characteristics of family support are:

- Recognising the need to support family members in their own right, and not simply as a source of 'recovery capital' for those who use substances
- Inculcating a warm, supportive, 'client-centred' ethos which is responsive to individual circumstances (rather than adopting a 'one size fits all' approach)
- Enabling the close involvement of family members in service design.

The project model was tailored to meet four outcomes:

Outcome 1

That family members in Greenwich will have greater knowledge of drugs and alcohol, including treatment options and of their rights as carers.

Outcome 2

That family members in Greenwich will gain support from their peers and feel less isolated and stigmatised.

Outcome 3

That family members in Greenwich will be more able to develop, run and manage their own sustainable services.

Outcome 4

That drug and alcohol users in Greenwich will have an improved chance of recovery, as their family members will be better supported.

What we achieved

Outcome 1: family members in Greenwich will have greater knowledge of drugs and alcohol, including treatment options and of their rights as carers.

This information was provided in the following settings:

- **Adfam's Family Information Sessions**: a rolling programme of six information sessions for family members and carers in Greenwich
- **Family Recovery Champion (FRC) training sessions** where family members who are experts by experience were trained to offer information and support to their peers
- **The Family Recovery Champion bi-monthly forums** which provided 'top up' training and information updates
- **Taking Steps**: a peer support group run by FRCs
- **The Family and Carers Newsletter** produced by FRCs for family members and carers
- **An information leaflet** produced by FRCs for family members and carers
- **One-to-one peer support** for family members and carers provided by trained FRCs when family members attended the Family Information Sessions or when they attended the local drug treatment service's drop-in with their loved one.

Since the start of the project 278 family members and carers accessed information which has given them greater knowledge of drugs and alcohol, treatment options and their rights as carers.

Prior to accessing support from this project, many family members described themselves as having little or no knowledge to assist them in caring for a loved one with a drug or alcohol problem.

What family members said

In the Taking Steps support group, family members frequently described how they thought they were doing the best for their loved one by doing everything for them, helping them hide their drug or alcohol use, helping them financially, and being supportive rather than challenging at all times. Since attending the group and accessing information about treatment and recovery, these family members have understood that setting boundaries for their loved one and taking care of themselves is an important component of all healthy relationships and all the more essential for their own recovery and for the recovery of the person with a drug or alcohol problem.

'You don't know who to go to; you are totally lost... There was nothing before the group. We didn't know anything.'

Family members and carers were clear that the information they accessed via this project was very valuable:

'It is only by coming to this group, it is by coming here that we get informed.'

'The knowledge from Adfam it has helped me to calm down from the madness around me. It helped me understand what was making my loved ones act the way they were.'

Outcome 2: family members in Greenwich will gain support from their peers and feel less isolated and stigmatised.

Since the start of the project, over 300 family members and carers were provided with direct support from a trained FRC either at the Taking Steps peer support group, at the Family Information sessions, or at the treatment service drop-in. Family members and carers frequently referred to how isolated they felt, how hard it was to seek support, and some have also mentioned how little support was available to them.

'It was the last resort [seeking help]. It is the shame. You don't tell anyone. I never told anyone. I didn't invite anyone round. I did not tell anyone.'

(Family Recovery Champion)

'It is shameful [the lack of support for family members and carers]…'
(*Participant in the Taking Steps peer support group)*

In the context of this shame, stigma and isolation, peer support can – and the evidence from this project strongly suggests does – provide family members with a space where they feel less isolated and stigmatised and can begin to talk openly about their concerns

Members of the support group began to support each other, with FRCs modelling resilience and positive coping strategies. The group functioned as a safe space for people to discuss very sensitive issues including isolation, rejection by other family members, violence and the fear that their loved ones would kill themselves.

What family members said

'It was the best thing we could have done, coming here… [you see] there is light at the end of the tunnel.'

'You feel safe because it's a small group. We're all mates. We phone each other and say "he's done this I need to get out of here".'

'It helps us to change our attitude towards it. A lot of people don't understand addiction. You think you are helping them but you are enabling.'

'It [the group] has saved us, hasn't it?'

'Whatever they tell you to do, do it. Before we came here we didn't know anything. If you listen to the advice you get [here] you'll end up on the right tracks. I can't praise them enough.'

‘You feel safe because it’s a small group. We’re all mates. We phone each other and say “he’s done this I need to get out of here”.’

Outcome three: family members in Greenwich will be more able to develop, run and manage their own sustainable services.

From the outset, the Whole Family Recovery Project sought to facilitate peer-led services run by family members for family members. This was achieved by:

- Facilitating a peer support group and providing one-to-one support.
- Establishing a FRC forum enabling FRCs to meet together every two months, to access additional training, to improve the service they could offer their peers, and to share ideas about how to develop peer support services to reach all those in need. This forum was established in response to the needs identified by FRCs and became a key source of ideas for the development of the project.
- Reaching out to family members in communities less likely to come forward and access help. Two Asian FRCs undertook outreach to their communities, with support from other FRCs who identified that widening access should not be a problem for those from diverse communities alone but should be shared by all the FRCs. FRCs attended the Royal Borough of Greenwich's third annual Asian Festival, coordinating the participation of the treatment provider and Adfam at the event. Adfam and the treatment provider's stalls attracted interest from hundreds of individuals including family members who spoke about their own experiences and took away information about local services.
- Piloting a peer support service at the treatment provider service's drop-in, acknowledging that accompanying your loved one to access treatment can be a uniquely frightening and isolating experience. Family Recovery Champions made themselves available in the reception area; reception staff would ask all family members accompanying a loved one to the service whether they would like to speak with a family member. Such was the demand for this service that Adfam increased it from a weekly service to a service offered three times a week.
- Writing and distributing a newsletter about the Whole Family Recovery project to raise awareness of the service among professionals working with families affected by substance misuse. The newsletter also served to inform those family members isolated at home and/or unable to access a face-to-face service. FRCs produced this newsletter themselves and widely disseminated it.
- Speaking at local, regional and national events, engaging family members, practitioners, commissioners and policy makers with their insights into the needs of family members and carers and their powerful advocacy for a continued investment in services for family members.

What people said

'We run the group. We put the ideas forward. It goes the way we want it.'
(Family Recovery Champion)

'Really wanted to say it was hugely brave of you yesterday being so open-hearted around such traumatic times with your son – found your talk incredibly helpful and uplifting.'
(Participant at a London conference)

Outcome four: drug and alcohol users in Greenwich will have an improved chance of recovery, as their family members will be better supported.

During the course of this project, we spoke to family members and carers who were not FRCs but who were attending the Talking Steps Peer Support Group for peer support for themselves. They told us how the support they had received helped them to better support their loved one.

What family members said

'Now, through coming here [Taking Steps], I realise just how hard drug use and alcoholism is it has made me a lot more tolerant. I didn't have an understanding before.'

'It is hard to realise that you need to do less for them… but she [staff member] has helped us set boundaries, she has guided us step by step.'

'Adfam have really changed my life. I drank to cope with his behaviour. I would not be sober without Adfam. I contacted Adfam because of speaking to [a FRC] and now I am in a positive place…'

(Participants in the Taking Steps peer support group)

Evidence of need

Throughout the project we heard many stories which highlighted the high levels of need of many family members affected by a loved one's substance use.

'He starts drinking between 4 and 6am every morning and currently drinks between 20 and 30 cans a day. He is 50 years old and his last detox lasted six weeks. He is not eating. He has lost a stone in four weeks. He is very tearful, beginning to cry each day after the first two or three beers. This has been going on for 15 years and I have just been in the shadows all this time. Sometimes you forget how to laugh.'

(Woman caring for husband of 29 years)

'You are so alone. You feel alienated from all your friends. They have no idea what it is like to live with someone misusing substances. So you stop even trying to explain.'

(Family Recovery Champion whose son died of a drug overdose)

By working in their communities, Family Recovery Champions became visible advocates, helping people to access services they would otherwise shun, thus challenging stigma and cultural mores.

The Whole Family Recovery Project: what we learned

Peer support can engage family members in a way that other services cannot

Family Recovery Champions were often the first point of contact for family members attending the treatment service drop-in. Many of these family members did not think that they needed support and would be unwilling to access a formal 'family support service'. For these family members, a FRC provides a listening ear and informal peer support from the basis of a shared understanding of how hard it can be to accept support in your own right.

Family Champions can see issues from the family member's perspective

Families see issues in a way professionals frequently cannot. For example, participants at a peer support session discussed how professionals speaking of 'setting boundaries' and 'letting a loved one hit rock bottom' can make sense in the safe setting of a counselling room but not within the chaos of family life – an understanding they felt that professionals, without lived experience, could not share.

Family members can be visible examples of recovery

By working in their communities, Family Recovery Champions became visible advocates, helping people to access services they would otherwise shun, thus challenging stigma and cultural mores.

The power of peer support

A couple in their 70s come to the drop-in. Mike has had a problem with drinking for years; his partner Kevin supports him.

Paul, an Adfam Family Recovery Champion, sees Mike and Kevin walk into the reception area and Mike is noticeably under the influence. Paul approaches the couple and introduces himself. Paul can see that Kevin is only interested in being there to support his partner and isn't open to talk about himself, so Paul leaves a leaflet with Kevin regarding family support.

The following week the couple attend the drop-in and Paul is there again, but it's clear that Kevin is still not open to receiving any support for himself. This time Paul strikes up a conversation about where they both live and identifies some experiences that they have in common. Paul also lets Kevin know he's there every Tuesday.

Three weeks later the couple attend the drop-in and Mike has an hour's appointment with treatment staff. Having gained a degree of trust through initial contact with Paul, Kevin sits with Paul for an hour and shares his story and for the first time talks about the difficulties he has experienced whilst supporting his partner.

Family Recovery Champions model of provision

Family Recovery Champions can offer a flexible, practical and tangible approach, for example, meeting a family member for a coffee. More formal services are unable to provide this. The skills and capacity of the 33 FRCs to identify and respond to the needs of their peers demonstrated they were more than capable of providing adequate support. The supervision and ongoing training provided by Adfam proved a critical element in being able to manage numbers and expectations.

The scale of need exceeded expectations

As the project developed, the level of need of the local community, both in terms of individual need and the needs of the group, in some cases exceeded expectations. In these cases we had to recognise the limitations of the support that volunteers could offer, and make sure that family members were signposted to services to give them the more intensive support they needed.

Peer support benefits those giving peer support, not just those receiving support

Testimonies from Family Recovery Champions underpin the research about the positive benefits of volunteering to volunteers themselves, including enhanced self-esteem and self-worth.

'FRCs are viewed differently. You are not Joe Blogg's partner, you are someone delivering a service.'

'I don't want to launch a national campaign and raise funds to change the world. But nor do I want to "move on and forget it ". I want to do something… I am keen to volunteer and do something.'

'My self-esteem, my confidence, my motivation… my engagement with Adfam has built me up as a person and has built my own personal development and has enabled me to work in the community and my work has been recognised and that has been so good for my self-esteem.'

'I like to give something back. I now volunteer here two hours a week and you develop relationships with people and feel you are going on a journey with them.'

'Even if just one person sees you at an event and takes a leaflet and gets help then that makes it all worthwhile.'

Peer support cannot take place in a vacuum

Our experience suggests that family support can only be developed if the project has the support of key agencies and services in the local community. We learned that collaboration and partnerships with, for example, the treatment provider, the local authority commissioner, the NHS treatment service, the carers' service and family community groups were crucial to the success of the project, both in terms of its credibility but also as a source of referrals. Whilst we would not advocate for Family Recovery Champion volunteers to replace funded services, they can add enormous value to existing provision if they are embedded within those services. There is also an understanding amongst staff at Adfam and partner agencies that FRCs can provide invaluable services alongside other agencies, but they cannot, nor should they be asked to, replace other provision:

'We want to build a network of family support so that there are different options… this is not to be a stand-alone or a replacement service. It is about increasing options for family members.'

(Adfam Family Support Development Co-ordinator)

Listening to families

One of the successes of this project lies in our responsiveness and the responsiveness of our partners to the ideas of the FRCs; it is by following their lead and listening to their lived experience that a service has developed that offers peer support when, and where, families need it in an accessible and supportive manner, leading to positive changes in the life experiences of hundreds of individuals.

Training and support for volunteers must be taken seriously, and volunteers need to feel valued

Our training was co-designed with family member experts by experience and they received ongoing support, supervision, and additional training. We recognised the contribution of the Family Recovery Champions by holding celebratory events, inviting volunteers to Adfam conferences and seminars, issuing achievement certificates, and by ensuring they had an Adfam name badge. All this meant that they reported they felt part of a team, and they were publically acknowledged.

'If people are running a group they need a chance to keep looking at boundaries and what is acceptable and what is not. For me that is a priority – to make sure FRCs are as safe as possible. A worker in this role would have all that in place – supervision, support, etc – so why shouldn't a volunteer have that too?'

(Family Support Worker, Partner Agency)

'The Forum… is an opportunity for group supervision, in a safe and welcoming space, where FRCs can identify their training needs and on-going development needs.'
Adfam Family Support Development Co-ordinator

'We have to be realistic about what we are asking them to do. By having support groups run by FRCs instead of just having six one-to-one sessions with me, people have more flexible support for longer.'

(Family Support Worker, Partner Agency)

Bringing service users and family members together

An unintended outcome of working in close partnership with the treatment provider has been the bringing together of service users and family members. The treatment provider also supports peer mentors and they cross-refer to the Adfam FRCs. The referral rate has been increased because trust has been gained with both groups of mentors – a trust that they are there to achieve the same aim, to support the family as a whole for the substance misuser and family member's benefit.

‘There’s nothing like talking to someone who’s been through the process of recovery themselves and has first-hand experience.’

Key learning:
the challenges

Finding the optimum partner organisations

The drop-in at the mental health and substance misuse treatment service attracted very few referrals, despite Adfam's best efforts. The Family Recovery Champions decided it was not a good use of their resources to continue to offer this service but they also agreed with Adfam that this lack of uptake was likely to be due to the stigma and shame attached to every aspect of caring for a loved one with a substance misuse issue. This stigma was likely to be even greater in the case of co-existing mental health and substance misuse. As a consequence, FRCs focused on working with a wide range of organisations in the Borough, raising visibility of the project within the community, raising awareness and thus challenging stigma.

Sustainability

Our funding from the Big Lottery comes to an end in March 2018. Having invested so much, and achieved so much, the case for continuing with this work is indisputable. However, funding, particularly in the current climate, is a challenge. The level of need and the effectiveness of this kind of support have been demonstrated, but with uncertain funding, it remains to be seen if and how the project can be sustained.

‘Just as they get ill together,
families get better together.’

Family Recovery Champions: our stories

Paul

62-year-old Paul has a 24-year-old son, Tom, who used to drink and use drugs. Since Paul first came into contact with Adfam three years ago, he has gone on to offer hope and inspiration to others as a Family Recovery Champion.

For Paul, the most difficult thing when his son Tom was misusing substances was the sense he had lost his son. He saw a diluted version of what he was. Paul's son was initially very resistant to professional help, so the whole family decided to go to therapy, in an effort to convince him. After a while, he began experiencing psychotic episodes. He was diagnosed with psychosis aged 18. At the time Paul accepted that this would be a slow journey and they 'adopted a "baby-step" approach to rehabilitating him back into "normal life".' His son had lost his confidence, was seeing his friends less and was suffering from anxiety. It was a struggle for Paul to come to terms with the drug use in general; he was constantly thinking I can, or should, do something about it, and realising he couldn't was sometimes overwhelming.

Since coming into contact with Adfam, things have changed significantly for Paul and his son. After two rehabs and two years of attending Narcotics Anonymous, Tom has gained recovery and is now studying counselling part-time and sees friends regularly.

Volunteering has made a big difference to Paul personally. As a Family Recovery Champion who attends the local treatment service drop-ins, Paul has got to know both service users and their family members. Paul feels this role has helped him to normalise substance misuse and its impacts on the family, reducing the stigma and shame associated with it. Paul says 'I find myself feeling comfortable now about speaking about my son's substance misuse, whereas in the old days I would have avoided speaking about it with friends'. For Paul, it is liberating and there is a sense of relief to be able to speak openly with the friends and family members he supports.

Paul shares that the best word he would use to sum up being impacted by his son's substance misuse is powerlessness. Doing the work of a Family Recovery Champion has given Paul a sense of power to be in a position to help others, and to do something useful with his experiences. It helps Paul put his own life into perspective and he feels it is an opportunity to feel good about himself. It can look like the problem lies just with the substance misuser, however Paul has learned it is only when you get closely involved that you realise it is a family problem. Paul says 'everyone gets ill together, except they don't know it at the time. Just as they get ill together, families get better together.'

Mary

Mary, a woman in early retirement, lives with her husband who drinks. The catalyst for Mary to seek support for herself three years ago was when her son started to experience his own problems because he felt let down by his father. Prior to becoming a Family Recovery Champion, Mary felt she was keeping a guilty secret to herself.

Mary met her husband when they were both teenagers. Her husband is her friend, her partner, her 'everything'. Whilst dealing with her husband's drinking and periods when he didn't drink, Mary began to develop anxieties as she felt she couldn't trust him and felt extremely let down by him. Mary knew that there must be support out there for families going through what she was going through and asked people in her local community. It was only when Mary did her own research on the internet that she came across the information sessions held in Woolwich.

The information sessions helped Mary to recognise that all the things she was feeling and suspected were in fact happening. She was able to see and have confirmed by a professional with the correct terms and knowledge what was happening, why it was happening and how it was happening; for Mary it 'opened my eyes to what I was suffering'.

For Mary, she had to make a choice to stay or leave her marriage. Mary decided to stay and therefore wanted to educate herself so that she would be able to stay without judging the situation.

Mary has been a Family Recovery Champion for the last three years. This is important for her as it gives her a focus of what she likes doing: supporting others. Mary believes that once family members have the tools that she gained in her own personal recovery, this allows family members to make the right decisions. In understanding other family members' situations, Mary feels she gets to understand her own situation more.

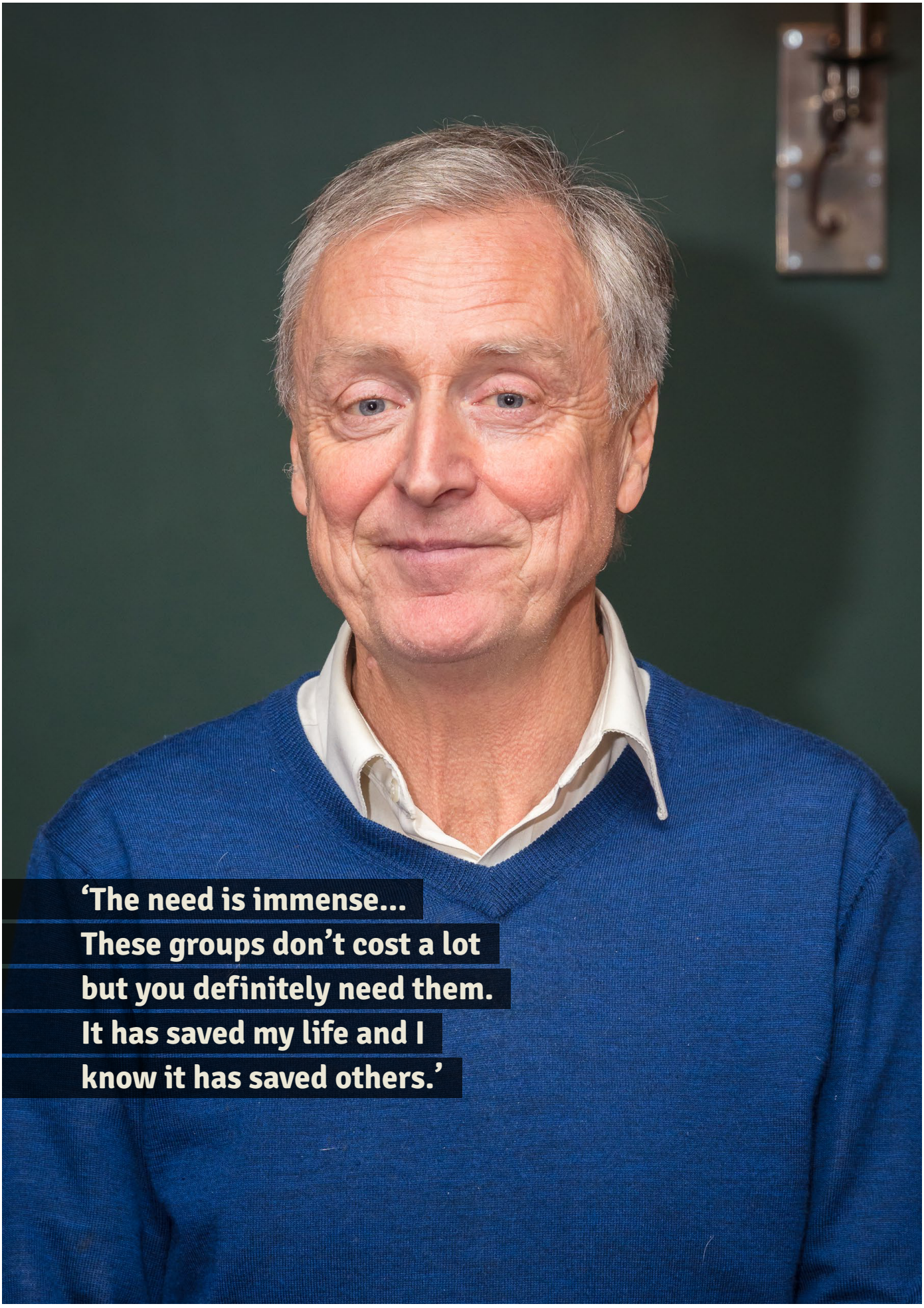
Amir

Amir had his own substance misuse issues and this had led him to get support from the local treatment service.

It was only when he started to experience problems with his son's misuse of cannabis that he was recommended to attend the local information sessions. Having attended this group, Amir felt he was in a much better position to support his son, and he wanted to offer his new found knowledge and understanding to other family members in similar situations.

'Now I have trained as a Family Recovery Champion I can support others using my own experience. I can help with breaking down the barriers and show it is not shameful to be in this position and that it is not shameful to ask for help. I can show them there is support out there. I can be there at events for the Asian community and show that you can get help and support from other members of the Asian community.'

Adfam would like to thank all of the family members who we spoke to as part of this report and who shared their stories with us. All names have been changed.


‘The need is immense...
These groups don’t cost a lot
but you definitely need them.
It has saved my life and I
know it has saved others.’

NATIONAL
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